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Designing Therapeutic Support for the People with Alzheimer's disease. A designerly way of Investigation

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Abstract: Alzheimer's disease (AD) is incurable but it is treatable; both drug and non-drug treatments of its symptoms are available. Non-drug therapies are consisting of physical and social components, which could be supported and assisted by designerly way of thinking. Besides, literature inquiry corroborates that new ways of interventions/approaches are desperately needed for the wellbeing of both the patients and their caregivers. In this research, person centred design approach is adapted. Accordingly, this research mind-set is set participatory, whereby healthcare professionals and patients' relatives are considered the experts and equal partners throughout the investigation process. Face to face interviews are conducted. Their real life experiences coping with the problematic symptoms are highlighted. In this direction their recommendations and suggestions are listed as design guidelines for the further investigations. Besides, the findings indicate that the created design concept which focuses on enhancing the patient's emotional state and keeping these positive emotions as long as possible by suggesting nonverbal commination cues as a tool could lead the upcoming researches in this area.

Keywords: Design, Alzheimer's disease, Sensors, Stimulants, Therapies

1. Introduction

1.1 Background

Dementia is the general term for the symptoms caused by Alzheimer's disease (AD). The most common symptoms occur in cognitive functions such as memory, thinking and behaviour, affecting the individual's daily routines. Dementia is usually seen in people older than 65 and there is a 20% increase in cases after the age of 80. The rate of change in the severity of dementia largely varies and fluctuates over time (Alzheimer Association, 2013).

First diagnosis of the Alzheimer's disease is attributed to Dr. Alois Alzheimer (hence the name) about 115 years ago. However 70 years should have passed before it was acknowledged as the prominent cause for dementia, constituting 60 to 80 percentage of the cases and it is a most certain cause of death (Alzheimer Association, 2016; Katzman, 1976). Much has been discovered ever since but much remains to be discovered as well. It is estimated that 40 million people suffer from AD in the world currently. By 2050 this number is expected to increase to 150 million. Any person who manages to live until 85 face the odds to suffer from AD or to take care of the significant other or a close relative who suffers from AD as the probability is 50% (Alzheimer Association, 2013; M Prince, Prina, & Guerchet, 2013; Martin Prince et al., 2015).

Alzheimer's disease (AD) is incurable but it is treatable. Best treatment efforts are known to be a synthesis of pharmacological and non-pharmacological therapies. Non-pharmacological treatment is multi faceted as it includes social, physical and environmental factors for the patient.

Accordingly, Zeisel (2009) underlines two uncommon common-sense messages:

- “1.The skills and capacities of people living with Alzheimer's that don't diminish over time, or do so more slowly, provide windows for connection and communication.
- 2.Through those windows lies opportunities to establish and build new and vibrant relationships that can sustain them and us over time, supporting both care and well being.” (Zeisel, 2009, p.4).

1.2 Problem

Behavioural and psychological symptoms of dementia (BPSD), also known as neuropsychiatric symptoms (NPS) cover a class of non-cognitive symptoms that are seen in the behaviour of dementia patients which generate great burden both for the patients and their caregivers. NPS affect the behaviour, thinking, perception and motor functions of patient as well as making the emotional state more fragile (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). Besides, these symptoms such as apathy, anxiety, agitation, aggression or depression, generates communication barrier between the patients, family member and therapists. In order to empower the “Triangle of Care”; associating nonverbal communication techniques along with technology would have a profound impact both on the quality of life for the patients and the effectiveness of therapies. In this line, new ways of assistance and support both for the therapies and the carers coping with emotional and behavioural problems are needed.

2. Design concept

AD is not a curable but treatable disease and treatment should include enhancing the patient's emotional state and providing for it as long as possible. First, reasons for the treatment to work should be explained. Zeisel (Zeisel & Raia, 2000) claim neurological based capacity remains for treatment. Amigdala of the brain's lymbic system is the part of us that regulates the emotions and our perception and response to emotion. Amygdala stays largely unharmed during the progress of AD so that the patient can still relate to others emotionally. The lost part is the reasoning of what could have triggered that particular emotion and the control over it. Treatment's main objective is to maintain the patient's ability to control emotional responses (Zeisel & Raia, 2000). Additionally, AD patients give away physical cues and nonverbal signals at all stages of the disease which simplify detecting their current emotional state. Those signals can easily be perceived by current ICT technology such as sensors. Different sensors that exist can be fit to the purpose at hand and

modified to the environment (i.e. nursing home or home) and to demographics (patient, family member caregiver, professional caregiver). Technological progress also allows the unification of multiplier sensors in one device (e.g. actigraphy, body temperature, audio recording) (Robert et al., 2013). Actigraphy has great potential, as there is no requirement for the carer to be present during recording. (Nagels et al., 2006)

This research assumes that ICT sensors and On the shelf technologies such as LEDs, Speakers, Vibration motor can generate innovative ways for supporting non-pharmacological treatments coping with emotional and behavioural problems as well as this approach can give a new form to “triangle of care”.

The main purpose of the concept is defining the negative emotions of the AD Patients and how to regulate them. BPDS, in which are most prevalent among the AD patients are Agitation, Aggression, Anxiety, Apathy and Depression, are considered as negative emotions and the concept is replacing them with the positive ones such as being calmed, relaxed, uplifted (happy), activated (excited). Nonverbal Communication is the key feature and a powerful tool for creating a meaningful treatment as well as maintaining the well being of the patients. Therefore, “communicating emotions through technology embedded design” concept is created.

3. Method

The investigation is based on exploring how Alzheimer’s patients and their carers both face with the neuropsychological symptoms of the disease and accordingly how design can assist them. In order to create a better understanding to the real life experiences of the patients’ family members and medical doctors in the field, in-depth interviews technique is adapted.

3.1 Settings

One-to-one sessions were scheduled with each interviewee. Besides, if preferred by the family members, the interviews took place at their homes. The style of the sessions was designed as narrative interview.

The questions were loosely structured to explore areas of communication problems, emotional and behavioural problems of the patients as well as the suggestions of the interviewees and discussions on design concept. Afterwards, these interviews were transcribed and categorized for analysis. Every interview session was took between 20 and 30 minutes and recorded. Explicit written consents were obtained before each interview. Then, these records are analysed and patients are grouped according to their backgrounds.

3.2 Respondents

Interviews are conducted with the assistance of Turkish Alzheimer’s Association Izmir Chapter. Participants are chosen from the applicants consisting of families of the patients, association related doctors, psychologists and professional caregivers.

Total number of participants is 24; 14 of them are Alzheimer’s treatment personnel, 10 of them are family members of the patients (Carers). In this context, two groups are formed.

In the first group, 14 healthcare professionals, the mean experience is 7.33 ± 2.109 (0-24) years with the disease, are reached from skilled nursing homes and Geriatric Department of University Hospital in Izmir. The range shows diversity, accordingly 2 participants have 0-2 years, 5 have 3-7 years, 5 have 8-12 years and 2 participants have 20 -24 years of experience in the field. In addition among

these participants, 10 are female while 4 participants are male. Alzheimer's treatment personnel participated in this study is consisting of 8 medical doctors, 4 psychologists specialized in Neuropsychology and 2 are caregivers. 3 doctors are specialized in Family Practice, 1 doctor is in Internal Medicine, 2 are in Geriatrics and 1 doctor specialized in Neurology, besides, one doctor has not specialized yet.

In the second group, 10 Carers (patients' relatives) are reached during the weekly meetings of Turkish Alzheimer Association Izmir Chapter. 9 are female while 1 participant is male, which indicates the female relatives are mainly taking the responsibilities of the patients. Accordingly, among 9 female relatives, 5 are daughters and 4 are the spouse of the patients. The only male patient relative has both parents are affected by Alzheimer's disease. On the other hand, when the education levels are compared, the half of the respondents hold the undergraduate degree, 3 hold high school degree and 2 holds middle school degrees. In a personal interview with Nil Tekin, who is currently the head of Turkish Alzheimer's Association Izmir Chapter, she suggested that Izmir is a city with high socioeconomic status. It is also one of the most preferable cities for the retired population and their families, mostly because of the convenient living conditions the city offers compared to other cities in Turkey (N. Tekin, Personal Interview, 27 February 2016).

4. Findings

4.1 Viewpoint of Healthcare Professionals

Communication Problems

7 among 14 healthcare personnel indicated that incoherent communication; giving wrong answers to the questions, not knowing what to say when, talking about irrelevant situations besides, talking about different topics at the beginning and end of the sentences, generates the most common communication problem. On the other hand, the other half of the interviewees mentioned that loss of words and limited understanding also cause the other main problem of the disease. Moreover, 3 interviewees underlined that hallucinations and delusions aggravate communication problems. Even sometimes hallucinations and delusions can be confused with communication problems.

Suggestions for communication

The replies of the interviewees differ from each other, which can be listed as; 3 of them suggested replicating the activity for instance by reminding how spoon works and asking the patient to repeat the action. 4 mentioned the benefits of art, music and socialization, 2 has mentioned how visual and verbal memory games can be effective practices. Finally 10 among 14 healthcare specialists described how important to use other ways of communication via attitude, physical contact, real-life objects and emotional state.

Behavioural and Emotional Disturbances

The interviewees got consensus on that instant agitation and aggression (instant hostility) are the most frequent disturbances encountered with the patients. Following that, introversion, depression, hallucinations and delusions as well as emotional instability problems are the mostly seen and create a much distress to the caregivers.

Time and frequency

8 of the interviewees agreed that darkness increases the fear of death feeling, and it agitates the patient. Agitation and negative disturbances starts from sunset/twilight gets worse at night time.

Nonverbal cues

10 of 14 interviewees stated that physical cues such as throwing stuff, cuddling some beloved objects, hitting and continuous movement state are the most frequent type of signs for any disturbances. On the other hand, vocal cues such as yelling, screaming, repeating the same sentence again and again, are yet another most frequent type of signs mentioned by the interviewees.

Carers' Awareness

The 10 interviewees suggested that the cares are mostly aware. Accordingly, one doctor added that if they cannot sleep they could tell the cause. On the other hand one interviewee pointed out that we are far from complete awareness about the Alzheimer's disease in Turkey For instance, you might see titles in newspapers like 'grandpa tried to stab granny: Because granny is unfaithful.' Grandpa sees the mirror but could not recognize his own face. He sees himself as a stranger. Two interviewees also added that some patient relatives do not want to understand and they are in denial. Though, it should be told properly to the patient relatives that it would never be the same again.

Suggestions for the disturbances

11 of 14 interviewees strongly agreed that listening to music/his son's voice/ audio are the foremost stimulant for the patients. Among 8 also mentioned that social and group activities have to be increased. Besides, 7 suggested that Physical environment is also significant and added in order to avoid accidents, interior spaces should be arranged accordingly. Creating distraction is another frequently stated topic among interviewees. One doctor suggested that shifting the focus, driving her away from agitating issues are too important for reducing the agitation. Yet, communication through attitude, emotions and physical contact by holding hand or patting the shoulder are the most promising methods to calm down the patient.

4.2 Viewpoint of Carers/Family Members

Realizing the disease

Except for one patient, who realised the disease by himself, all the interviewees reported that they realise the disease symptoms with the behavioural anomalies such as seeing things that are not there and changing habits.

Communication Problems

All the respondents stated that most distressing communication problem is inability to describe problems by words. They described that they could only communicate via body language or vocal expression such as showing the stomach when the patient needs to go to toilet or making some noises, which indicates that he is content or disturbed. Moreover, 5 interviewees added that loss of words such as shortened sentences and using the same words, is another frequently encountered problem among patients.

Behavioural and Emotional Disturbances

Same as the healthcare personnel, 8 of 10 patient relatives participated also mentioned that Aggression, agitation, tantrum and yelling are the most common disturbances that makes the carers overwhelmed and distressed. Yet again most of the respondents added that hallucinations and delusions, depression, high anxiety and sleeping disturbances are also other mostly common disturbances that the carers have to face with.

Favourite object

Only 3 among 10 patient relatives stated that their loved ones have dependence on some belongings such as wallet and clothing.

Nonverbal Cues

Most of the respondents stated that making vocal cues and physical cues are the most common nonverbal communication signs for their loved ones.

Overall Suggestions

Same as Alzheimer's treatment personnel, Patient relatives suggested listening to music calms down the patients. They also mentioned that using approval method not to disagree about their ideas and inventing housework activates like separating the beans make their loved ones more calm and manageable. Besides, they suggested that communication via physical contact like hugging and holding hand makes the patients more positive.

4.3 Design Recommendations and Suggestions

During the interviews the last part was the discussion of the design concept. In this direction the below design guidelines are collected and listed.

Safety and 'Feeling safe' are first to be considered!

- Designed product should be water and shock resistant. Some patients can behave like babies; therefore device components should be resistant and resilient. Patient safety should also be taken into account.
- New devices should not agitate AD patients. These devices should be disguised as everyday objects.
- "I'm safe, I am home" It is important to adapt the patient to the current time and environment.
- Patients have the fear of darkness and loneliness. That's why they feel better in well-illuminated spaces.

Have simple solutions!

- Instead of using a complicated set of buttons, intuitive activation methods should be used (i.e. pulling, squeezing, hitting).
- Plush toys have calming effect for many patients. Design ideas based on these toys can be helpful.

Be aware of special needs!

- Night hallucinations are common in AD patients that are why fall is frequently observed. Fall sensitive products can be useful.
- Orthopaedic products should be designed for patients that are confined to bed.
- System should be personalized.
- A product design that can help patients who cannot tell they have to defecate or already defecated to their adult diaper could be of significant help.
- Agitated patient's focus should be diverted; any prospective design should take this into account.
- Vision and hearing problems are common in elderly people. Design should adapt to these handicaps

Monitoring is crucial for treatment!

- New devices, which can track patient activity during the night, can be significant in sleep behaviour disturbance diagnosis.
- New devices to continuously track of patient vitals specifically designed for nursing homes.

Sensory Stimulants are the key features!

- Auditory: Familiar voices are important for the patient. Music is a prominent stimulant. In addition, songs sung by the patient with the caregiver can be recorded and played again. Like a baby sleeps listening to heartbeat in its mother's womb; a synthetic 70bpm heartbeat effect can help AD patients regulate their sleeping patterns.
- Visual: Twilight syndrome is common in AD patients. That's why during dusk, daylight can be applied. But at night, that light should be softer and low so that patient's sleeping pattern is not disrupted. Bright colours should be used in the design that the patient can adopt that object. It can also be personalized with the patient's name or picture. Daylight is stimulant but a low light such as a candlelight have relaxing effect and help sleeping.
- Olfactory: Smell has a calming effect. Aromatherapy, such as lavender smell can help. An automatic aroma spray mechanism can be used embedded in everyday objects.
- Haptic/Tactile: Imitating touch "Someone is touching me, there is a person beside me" feeling. If it can be given with vibration and light temperature, patient will feel safer. Physical stimulants can be used in different parts of the body. A substitute that can imitate the sense of touch with vibration can be useful. When the patient is agitated, we search for something for the patient to hold to be distracted like holding his hand.

4. Conclusion

This paper originally covers the investigation part of the PhD level research which examines a new way of therapeutic support for Alzheimer's patients and their caregivers. In this end, the study had three goals: (1) to assist Alzheimer's patients gaining more benefits from the non-pharmacological therapies or, even slowing down the progress of the disease symptoms, (2) to create a smart tool to enhance the communication between the therapist, carer and the patients and (3) to bridge the gap between design and dementia therapies by proposing a theoretical background and finally to create a baseline for the further studies. Therefore, the findings of the investigation described in this paper highlighted that emotional and behavioural disturbances create a communication barrier both for the formal and informal caregivers. In order to achieve these problems and burdens design related approaches are desperately needed. One of the interviewee made a comment, which summarizes the situation very clearly:

"When you are in a rough situation, people tend to buy anything if they think it will help them even if it is hard to afford. Even the slightest support is needed."
(Interviewee 5, Family member, 26 February, 2016)

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